

Goal Development in Parents of Children with Epilepsy and Learning Disorders

¹**Lindsey Keener**, BSN Honors Student, ²Wendy Miller, R.N., Ph.D., ²Janice Buelow, R.N., Ph.D.

¹Indiana University School of Nursing, ¹Indiana University-Purdue University Indianapolis; ²The Epilepsy Foundation- Vice President of Programs and Research. Indiana University-Purdue University Indianapolis

Epilepsy is the most common, chronic neurological condition in children, impacting 2.4 children per 1,000. Caregivers of children with epilepsy and learning disorders are affected by many confounding factors including complex drug regimens, navigating a complex healthcare system, the uncertainty of their child's future and the challenge of creating an effective educational program in conjunction with their child's school.

Parents of children with epilepsy and learning disorders participated in the Creating Avenues for Parent Partnerships (CAPP) program. The original study was an experimental design in which parents were randomly placed in an intervention group or a wait list control group. Each group consisted of 25 parents, with a total of 50 parents participating in the pilot test of CAPP. One of the instruments that the parents completed throughout the duration of this interventional program was the Goal Attainment Scale (GAS). In the GAS, parents described their goals related to their child's condition and care. Using a qualitative and systematic coding system the parent's goals were categorized based on content and outcomes related to their child.

The goals created by parents in this population subset fell into eight distinct categories. The categories discerned during analysis were future oriented, internal/perspective adjustment, interpersonal, maintaining normalcy, education/coordination with schools, interaction with health care professionals, physical fitness, and acknowledgement/fostering independence..

Based on analysis of the goals that parents created within the GAS, parents of children with epilepsy are particularly concerned with the security of their child's future (both residentially and vocationally), educational advancement in partnership with schools, and improving health status through interaction with health care professionals. For the nurse interacting with patients and their caregiver in this specialized population it is critical to understand the goals that caregivers create in relation to the problems that they perceive as the most significant in their lives. Then the nurse will be able to enable caregivers to meet their goals and improve the health outcomes and overall quality of life in children with epilepsy and learning disorders.

Mentors: Wendy Miller, Department of Adult Health, Indiana University School of Nursing, Indiana University-Bloomington; Janice Buelow, Department of Adult Health, Indiana University School of Nursing, Indiana University-Purdue University Indianapolis.